Approved – 6/17/14

**MINUTES OF THE MAY 20, 2014 MEETING OF THE
PATIENT CONSENT PREFERENCES AND DATA SECURITY WORK GROUP
OF THE ILLINOIS HEALTH INFORMATION EXCHANGE AUTHORITY**

The Patient Consent Preferences & Data Security Work Group (Work Group) of the Illinois Health Information Exchange (ILHIE) Authority, pursuant to notice duly given, held a meeting at 2:00 p.m., on May 20, 2014, at the offices of the Authority, State of Illinois James R. Thompson Center, Room 2-201, 100 W. Randolph St., Chicago, IL 60601, with telephone conference call capabilities.

Welcome to the Meeting and Roll Call

Elizabeth LaRocca from GOHIT welcomed everyone to the meeting and took roll call.

Attendance in Person	Attendance via Telephone
Elizabeth LaRocca, GOHIT	Sherri DeVito, Illinois State Medical Society
Roshni Shikari, ACLU, on behalf of Colleen Connell	Paul Geiser, University of Illinois
Howard Lee, Wirehead Technology	Nick Bonvino, Southern Illinois Health Information Exchange
Krysta Heaney, ILHIE Authority	Amanda Attaway, Illinois State Medical Society
Ivan Handler, ILHIE Authority	Mike Berry, HLN
Peter Eckart, Co-Chair, Illinois Public Health Institute	Dr. Carl Gunter, University of Illinois / SHARPS
Harry Rhodes, Co-Chair, American Health Information Management Association	Mikki Pierce, Atrium Advisory Services
	Ratiyand Goyle, Cyper
	Jennifer Routzon, Central Illinois Health Information Exchange
	Jim Wilkerson, Mental Health Centers of Central Illinois

Ms. LaRocca stated that the meeting notice and agenda was posted more than 48 hours in advance of the meeting in accordance with the Open Meeting Act.

Peter Eckert noted that the work group is in the process of reviewing possible technical solutions for data security and patient consent. He noted that the final recommendation to the ILHIE Authority would be drafted at the next meeting.

Approval of Minutes

The work group approved the minutes from the April 22, 2014 meeting.

Review of Draft Analysis

Mr. Eckert drew the work group's attention to the draft of the analysis matrix. He noted that the work group had completed Data Segmentation for Privacy at the last meeting. Mr. Eckert noted that the work group would focus on SHARPS and the audit trails. As a

reminder to the work group, Mr. Eckert noted the seven questions that the analysis matrix focuses on.

SHARPS presentation

Dr. Carl Gunter made a presentation on SHARPS. He began by going into the background of how SHARPS was created. He noted that "access controls and audits" and "data segmentation and identification" are the two areas of research on SHARPS that the work group has focused on. Witness testimony shows that patients are concerned with sharing their health data in certain contexts. The main question is how can technology be developed to help segment patient records and how does that affect the process of exchanging information. The SHARPS case study designed to answer this question focused on patients with HIV. Dr. Gunter drew the work group's attention to the intermediate outcomes of the HIV case study designed to address the feasibility of breaking up patient records.

Dr. Gunter then moved into a discussion explaining his work with Decision Support for Data Segmentation (DS2) and the background of the ILHIE Prototype. He then turned the discussion over to Mike Berry to explain the ILHIE Prototype.

Discussion of the ILHIE Prototype

Mr. Berry drew the work group's attention to the three core functions in DS2: the predicate, the reducer or redaction, and the safety checker. Mr. Berry explained each function and their relation to one another.

A speaker asked what would happen if the safety checker revealed that a certain medication that had been redacted could not be combined with a medication that a doctor wanted to prescribe? The speaker asked what the safety checker would reveal in such an instance.

Mr. Berry noted that the system would warn, but would not go any further. He explained that the doctor would have to then talk to the patient to obtain further information. The work group agreed that doctors could not be stopped from making inferences about redacted information.

A speaker commented that how the safety checker is applied would depend on the policy of the organization.

Mr. Berry continued on to explain a diagram of the predicate reducer architecture. A speaker commented that this architecture is general and could potentially be used for any HIE.

Mr. Berry moved on to give an example of a problem list of an HIV patient and how the predicate reducer would evaluate the problem list.

A speaker commented on how quickly a patient's record could become stripped by the predicate reducer.

Mr. Berry noted that the key challenge is to remove information from the patient's record that a patient does not want to reveal while still maintaining the integrity of the record.

A speaker commented that doctors might not have access to any information about a patient if that patient refuses to participate in the exchange.

Mr. Berry continued on and discussed two reports that were produced after looking at problem lists from pilot participant and publicly available data sets. He noted that the first report describes the technical architecture of the clinical decision support framework and the second report details contextual integrity and policy issues.

Mr. Berry then briefly discussed a web application called the Inference Analyzer that allows the user to explore patient data sets and how various predicates might react to patient records. Mr. Berry explained that the application runs different predicates through patient records to redact clinical facts and re-run predicates. He noted that the application was not intended to be used in the field, but to give users a better understanding of the system.

A speaker offered further clarification of the application by drawing the work group's attention to a specific example in the presentation on how to use the application where a patient's HIV diagnoses had been hidden.

Another speaker asked how often predicates would be run on a patient's records.

Mr. Berry explained that information would be redacted from a patient's records until the predicate returned false, meaning less than a 50% probability that a patient suffers from the condition intended to be hidden.

Mr. Berry noted that in an HIE environment the system would automatically redact documents.

Mr. Berry continued on to present results of a comparison between the machine based predicates and more traditional approaches that were used on 150 NMH patients with HIV.

Mr. Berry moved on to discuss the challenges of explaining machine based learning predicates to patients and doctors as opposed to rules based clinical decision support.

Mr. Berry then briefly discussed other areas that could benefit from the prototype and detailed where people could find out more information about the prototype. He also noted that the software was in fact a prototype and is not in the pilot stage of development.

A speaker commented that any type of data filtration is based on current statutory framework and that there is no way to predict hfuture changes.

Another speaker noted that the work group was not yet prepared to recommend a technology at the June 17th meeting.

Mr. Eckert asked the group whether the matrix should be filled out for SHARPS at this meeting or whether it should be saved for a later date.

The work group agreed that while some of the questions in the matrix could not be fully answered, the matrix would be completed before the June 17th meeting.

Mr. Gunter noted that the DS2 technology might not be up to the work group's standard for readiness, but that the audit technology side of SHARPS was further along in terms of practical application.

A speaker commented that none of the platforms the work group has looked at are ready for immediate implementation.

Discussion of Personas

The group then discussed the development of the personas. Mr. Eckert noted three documents on the personas had been drafted and distributed to the work group. Mr. Eckert briefly discussed the persona document he drafted and noted that most of the information he used came from the US Department of Health and Human Services and the Illinois Department of Public Heath.

Mr. Handler briefly discussed the HIV persona he had drafted and noted that people with HIV or any disease will differ in what kind of information they want protected.

Mr. Handler moved on and presented his paper on patient provider relationships. He discussed whether patient information should be kept within the treatment domain so that people who are not directly involved with a patient's treatment will not be allowed access to the patient's information.

A speaker commented on the possibility to combine some of the vendors' products in order to create a more commercially viable system.

Next Steps

Mr. Eckert announced that the next meeting is scheduled for June 17th 2014 and noted that the work group must have a recommendation draft for the ILHIE Authority by the date of this next meeting. As such, Mr. Eckert noted that the draft should be completed by June 10th.

Public Comments

Jim Wilkerson noted that he had drafted the behavioral health persona and inquired as to whether or not the personas should be included in the recommendation draft.

The work group agreed that the personas did not need to be completed by the June 17th meeting.

The meeting adjourned.